Creutzfeldt-Jakob Disease (CJD) Case Report Form
Arizona Department of Health Services
Office of Infectious Disease Services
150 N. 18th Ave., Suite 140
Phoenix, AZ 85007-3237

Note to local and/or state health investigator: Complete this form for all persons diagnosed with or suspected of having CJD. Obtain and review, if available, the patient's hospital admission and discharge summaries, EEG and MRI reports, neurology and psychiatric consultation notes, brain biopsy reports, and autopsy reports and send copies to ADHS with this case report form.

Case Classification
Prion Disease Classification
- ☐ Sporadic CJD (indicate whether the diagnosis is a definite, probable, or possible case of CJD)
  - ☐ Definite CJD
  - ☐ Probable CJD
  - ☐ Suspect CJD
- ☐ Familial prion disease; specify _____
- ☐ Iatrogenic CJD
- ☐ Ruled Out, specify: _____

Reported By
Name: _____
Organization: _____
Phone No. (_____) _____
Date form completed: _ _/_ _/_ _ _ _ (mm/dd/yyyy)

Contact Information
Current physician's name: _____
Phone number: _____
Mailing address: _____
Name of family contact: _____
Phone number: _____
Has the family been contacted? ☐ Yes ☐ No
Has family indicated that the health department may contact them again?
1☐ Yes, may contact
2☐ No, may not contact
3☐ No indication has been made by family
4☐ Unknown
5☐ Other (specify _____)

Patient Information/Demographics
I. General Information
MEDSIS ID: _____
Patient First Name: _____
Patient Last Name: _____
Date form filled out: _ _/ _ _/_ _ _ _ (mm/dd/yyyy)
State of residence: _____ County of residence: _____
Date of birth: _ _/_ _/_ _ _ _ (mm/dd/yyyy) Age at death: __ __ years ☐ Still Alive Sex: 1 Male 2 Female
Ethnicity: 1 Hispanic or Latino 2 Not Hispanic or Latino
Race (mark one or more): 1 White 2 Black or African American 3 Asian 4 Native Hawaiian/Other pacific islander
5 American Indian/Alaska Native 6 Unknown
Month and year of initial symptoms:_ _/_ _ _ _ (mm/yyyy) Date of death: _ _/_ _/_ _ _ _ (mm/dd/yyyy)
Is CJD listed as a cause of death on the certificate? 1☐ Yes 2☐ No 9☐ Unknown
If CJD was <u>not</u> listed as a cause of death, what was the <u>primary cause of death</u> as documented on the death certificate?_____

II. Clinical Information
Date of illness onset: _ _ /_ _ _ _ (mm/yyyy)
Date of diagnosis of CJD: _ _ /_ _ _ _ (mm/yyyy)
Name (and location) of hospital where CJD diagnosis was made: _____
Date of initial report to the health department: _ _ /_ _ _ _ (mm/yyyy)

Duration of illness: __ __ months

Was the patient seen by a neurologist? 1☐ Yes 2☐ No 9☐ Unknown

Who diagnosed the patient with CJD? 1☐ Neurologist 2☐ Primary care physician
3☐ Other (specify: _____)

Did the patient have any of the following: (Note: If these specific clinical indicators are not mentioned in the medical records but there is wording that might be interpreted as one of these indicators, you are encouraged to discuss those findings with the neurologist or with ADHS before making clinical assumptions.)

Progressive dementia	1☐ Yes	2☐ No	9☐ Unknown
Myoclonus	1☐ Yes	2☐ No	9☐ Unknown
Visual deficits	1☐ Yes	2☐ No	9☐ Unknown
Cerebellar signs (e.g., poor coordination/ataxia)	1☐ Yes	2☐ No	9☐ Unknown
Pyramidal/extrapyramidal signs	1☐ Yes	2☐ No	9☐ Unknown
Akinetic mutism	1☐ Yes	2☐ No	9☐ Unknown

III. Laboratory Testing

Were any EEGs performed? 1☐ Yes 2☐ No 9☐ Unknown
If yes, did a radiologist or a neurologist report that an EEG was indicative of a CJD diagnosis?
1☐ Yes 2☐ No 9☐ Unknown
Findings: _____ Date: ___/___/_____

Were any MRIs performed? 1☐ Yes 2☐ No 9☐ Unknown
If yes, did a radiologist or a neurologist report that an MRI was indicative of a CJD diagnosis?
1☐ Yes 2☐ No 9☐ Unknown
Findings: _____ Date: ___/___/_____

Were any CSF specimens sent to the National Prion Disease Pathology Surveillance Center (http://www.cjdsurveillance.com)?
1☐ Yes 2☐ No 9☐ Unknown

If yes, date of lab report: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy) or ☐ Unknown
Result of testing:

Initial 14-3-3	1☐ Positive	2☐ Negative	3☐ Ambiguous	9☐ Unknown
Repeat 14-3-3	1☐ Positive	2☐ Negative	3☐ Ambiguous	9☐ Unknown

Was a brain biopsy performed? 1☐ Yes 2☐ No 9☐ Unknown
If yes, date of lab report: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy) or ☐ Unknown
Results of testing: _____ or ☐ Unknown

If yes, were biopsy specimens sent to the National Prion Disease Pathology Surveillance Center?
1☐ Yes 2☐ No 9☐ Unknown

Was an autopsy* performed? 1☐ Yes 2☐ No 9☐ Unknown
If yes, were autopsy specimens sent to the National Prion Disease Pathology Surveillance Center?
1☐ Yes 2☐ No 9☐ Unknown
Western Blot: 1☐ Abnormal Prion Protein Present 2☐ Abnormal Prion Protein Not Present
Immunohistochemistry 1☐ Positive 2☐ Negative

*Note: Neuropathlogical examination of brain tissue is the only way to confirm Creutzfeldt - Jakob disease.

Was blood or tissue sent to the National Prion Disease Pathology Surveillance Center for genetic testing?
1☐ Yes 2☐ No 9☐ Unknown

If yes, date of lab report: _ _ /_ _ /_ _ _ _ (mm/dd/yyyy) or ☐ Unknown
Results of testing: PRNP mutation present? 1☐ Yes 2☐ No 9☐ Unknown
Results of testing: Codon 129? 1☐ Methionine/Methionine 2☐ Methionine/Valine
3☐ Valine/Valine 9☐ Unknown

Were any other types of testing performed to diagnose CJD in this patient?
1☐ Yes 2☐ No 9☐ Unknown
If yes, what kind of test was performed and what were the results of testing?
_____
_____

IV. Relevant Past Clinical History

Is there history of a definite or probable case of prion disease in a blood relative?

1☐ Yes 2☐ No 9☐ Unknown

If yes, what was relationship to patient? _____

Did the patient undergo any of the surgical procedures listed here before onset of the current illness? (If there was more than one surgery in a given category, so indicate and provide the year of each surgery, if known.)

Brain surgery	1☐ Yes 2☐ No 9☐ Unknown	Year _ _ _ _ (yyyy)
Spinal surgery	1☐ Yes 2☐ No 9☐ Unknown	Year _ _ _ _ (yyyy)
Eye surgery	1☐ Yes 2☐ No 9☐ Unknown	Year _ _ _ _ (yyyy)
Sinus surgery	1☐ Yes 2☐ No 9☐ Unknown	Year _ _ _ _ (yyyy)

Did the patient ever receive:

A dura mater allograft?	1☐ Yes 2☐ No 9☐ Unknown	Year _ _ _ _ (yyyy)
A corneal allograft?	1☐ Yes 2☐ No 9☐ Unknown	Year _ _ _ _ (yyyy)
Human derived pituitary growth hormone?	1☐ Yes 2☐ No 9☐ Unknown	First year of receipt _ _ _ _(yyyy) Last year of receipt _ _ _ _ (yyyy)

Did the patient ever donate blood? 1☐ Yes 2☐ No 9☐ Unknown

If yes, when was the last time the patient donated blood? _ _/_ _/_ _ _ _ (mm/dd/yyyy)

In what city and state did the patient last donate blood? _____

FOR PATIENTS ≤55 YEARS OF AGE

Other Information

Did the patient live or travel (including military service) in the United Kingdom between 1980 and 1996?

1☐Yes 2☐ No 9☐ Unknown If yes, list specific years _____

Did the patient live or travel (including military service) in other European countries between 1980 and 1996?

1☐Yes 2☐ No 9☐ Unknown

Specify country:_____ List specific years _____
Specific country:_____ List specific years _____
Specific country:_____ List specific years _____

Did the patient ever hunt deer or elk in CO, WY, or NE (circle relevant states)?

1☐ Yes 2☐ No 9☐ Unknown

If yes, provide details (e.g., state and area hunted, year hunted)_____

_____

_____

Did the patient ever hunt deer or elk in IL, KS, NM, NY, SD, UT, WI, or WV (circle relevant states)?

1☐ Yes 2☐ No 9☐ Unknown

If yes, provide details (e.g., state and area hunted, year hunted): _____

_____

_____

Did the patient ever knowingly eat deer or elk meat from CO, WY, or NE (circle relevant states)?

1☐ Yes 2☐ No 9☐ Unknown

If yes, was the meat known to have tested positive for CWD? 1☐ Yes 2☐ No 9☐ Unknown

If the patient did knowingly eat deer or elk meat, provide details: _____

_____

_____

Did the patient ever knowingly eat deer or elk meat from IL, KS, NM, NY, SD, UT, WI, or WV (circle relevant states)?

If yes, was the meat known to have tested positive for CWD? 1☐ Yes 2☐ No 9☐ Unknown

If the patient did knowingly eat deer or elk meat, provide details: _____

_____

_____